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| 13. ABSTRACT (Maximum 200) The revolution in information technology is demonstrated by the dramatic increase in use of the Internet. Use of email and the World Wide Web (WWW) have become commonplace, potentially linking tens of millions of people worldwide. While the WWW has been embraced as a means for information dissemination, its use in an epidemiologic context is in its infancy. The survey capabilities of the WWW suggest the possibility of cost-efficient data collection from large numbers of people. The Epidemiologic Cyberspace Cohort Study is examining the feasibility of enrolling and following participants for a cohort study of diet, other factors, and breast cancer and other chronic diseases. Feasibility will be determined by: the number and demographic profile of study participants; the stability and use of email addresses for follow-up; and validity of responses. Technical aspects of feasibility include assurance of confidentiality, design of user-friendly survey forms, use of incentives for participation, and methods for data capture and tracking of participants. ECCSite!, the website of the Epidemiologic Cyberspace Cohort Study, was launched on June 6, 1997 (URL: http://epihub.epi.umn.edu/~health_survey/health_survey.htm). Through July 30, 580 participants had enrolled in the study. If feasibility of the WWW for collecting data and for short-term follow-up is demonstrated, this should provide a basis for conducting large, timely, and cost-efficient prospective cohort studies. | | | |
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FOREWORD

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INTRODUCTION

This Annual Report describes the progress made on the grant, "Feasibility of Breast Cancer Epidemiology on the Internet" (DAMD17-96-1-6105). The purpose of the study is to examine whether the World Wide Web can be used for the conduct of prospective epidemiologic studies of diet, lifestyle, and breast and other cancers. The rationale for this study lies primarily in the potential of the Internet to provide inexpensive, highly-efficient data collection and follow-up of large numbers of individuals. Just as email has come to replace or complement regular postal service in many contexts, surveys on the Internet may, under some circumstances, be a substitute for mailed questionnaires in epidemiologic studies.

Large, mail-questionnaire-based prospective cohort studies have provided important information regarding the association of dietary factors and other risk factors and risk of breast cancer and other diseases. Examples of these studies include the Nurses' Health Study, comprising about 90,000 women with dietary information who have been followed since 1980 with mailed follow-up surveys every two to four years (1), and the Iowa Women's Health Study, consisting of over 40,000 women in Iowa who have been followed since 1986 (2). Seven such studies, involving over 300,000 women, have been collaborating to examine associations of dietary and other risk factors for breast cancer (3,4). These studies typically involve the mailing of questionnaires that collect information on dietary habits, reproductive and medical history, lifestyle factors such as physical activity and cigarette smoking, demographic information, and various other factors that may be related to breast cancer risk. With follow-up of cohort members for breast cancer occurrence, usually confirmed through medical records or cancer registries, it is possible to relate questionnaire information to risk of developing breast cancer. In the Iowa Women's Health Study, for example, we have reported that breast cancer risk is associated with a higher waist-to-hip ratio (5), increases with increasing alcohol intake (6), is only modestly and weakly associated with dietary fat intake (2,7), and is unrelated to intakes of vitamins A, C or E (8).

Advances in the design and execution of large-scale epidemiologic studies appear to be moving in two directions. First, several studies are attempting to incorporate collection of biological samples as part of data collection. Such tissue samples may be used for evaluation of various biological markers of exposure or cancer risk, including gene polymorphisms. Since study participants are often widely distributed geographically, examination of biological markers are limited to those that can be examined in tissues that can be collected by mail and that do not require immediate processing. The other direction in which such large-scale studies of diet and cancer have been moving has been to develop methods to establish cohorts that are more likely to provide information about dietary exposures and cancer risk. For example, a large-scale multiethnic cohort study is being conducted in the Los Angeles area and Hawaii, with the idea that there will be greater variation in dietary exposures by enrolling substantial numbers of Japanese Americans, African Americans, and Latino populations in the cohort (L. Kolonel, personal communication). Similarly, we are involved in the establishment of a cohort of

approximately 75,000 women in Shanghai, partly to examine whether dietary fat may be associated with breast cancer risk in a population of women consuming diets that are substantially lower in fat than found in the U.S. This feasibility study of examining whether the Internet can be used for such studies also will examine whether substantial variation in dietary habits can be achieved by potentially enrolling cohort members from the US and around the world.

Specific technical aims of this project are to pretest and implement a survey that would be placed on the World Wide Web, to ensure confidentiality of responses, to develop methods for follow-up of respondents, and to establish a website for the study. Scientific objectives include describing of the demographic profile and nutrient intake profile of cohort members, determining the short-term and long-term reliability of dietary information, and determining six-month follow-up rates for the cohort. These efforts should provide a basis for determining whether the epidemiologic cohort studies of diet and cancer can be conducted through the Internet.

To date, we have successfully established a website for the study, which we call ECCSite!, the website of the Epidemiologic Cyberspace Cohort Study, and which can be reached at http://www.epi.umn.edu/health_survey/health_survey.htm. Plans for this year include the conduct of the reliability study, and implementation of follow-up procedures.

BODY

Experimental Methods, Assumptions, and Procedures

The primary methods that are being implemented for this study relate to collection of survey information that is posted on the World Wide Web. The survey instrument consists of several sections, including modules on: demographics; lifestyle factors such as physical activity, cigarette smoking, and a weight history; a food frequency questionnaire that is itself divided into several modules; vitamin and other supplement intake; medical history; reproductive history; and a final module on other information. A list of the various questionnaire modules is provided in Appendix 1; sample modules are also provided in this appendix. Potential participants may connect to our website to fill out our survey, and by doing so become a member of our cyberspace cohort.

At the six-month anniversary of complete submission of information to our study, we will be provide access to follow-up questionnaires on our website. Cohort members will be sent an email message notifying them that they are invited to return to our website to fill out the follow-up questionnaire. This will provide information about follow-up rates, as well as provide initial indications of the occurrence of some endpoints of interest, including breast cancer. However, as the follow-up period will be relatively short, analyses relating baseline questionnaire information with incidence of breast cancer or other endpoints are not planned.

Reliability and validity of the WWW survey information will be examined by comparison with information from regular mailed surveys. These surveys will be mailed to cohort members who have agreed to participate in such a validation study.

ASSUMPTIONS

The study clearly will involve participants who are self-selected. In addition, the participants will by necessity have access to the World Wide Web, and are required to have an email account by which they can register to our site. However, because the purpose of the study is to establish a cohort that will be followed over time, selection should not be an issue unless the association of dietary habits or other factors with disease is related to whether a person can and decides to participate in the study. While dietary habits may differ from the general population, and disease rates may also differ from the general population, the association between the two should be unrelated to participation.

Ultimately, we are assuming that the vast majority of participants will respond to our survey as accurately as possible. However, we are planning to conduct a validation study using accepted epidemiologic methods to provide an estimate of whether this is the case.

PROCEDURES

Introduction to the Website

Initial launching of the study and announcement of the website has been relatively cautious, in order to discover bugs or errors by users that we had not anticipated. On June 6th, 1997, the study website was listed on 16 of the most commonly-used Internet search engines, including Altavista (<http://altavista.digital.com>), yahoo (<http://www.yahoo.com>), and Excite (<http://www.excite.com/>). It was also promoted over the following few days on several listserv discussion groups, including groups focused on epidemiology, health informatics, dietetics, and breast cancer. A copy of the email notice is included in Appendix 2. The study has also been mentioned in the newsletter, *The Epidemiology Monitor* (9); a copy of this article is also provided in Appendix 2. The editor of this newsletter found out about the study through a poster presentation we made at the Annual Meeting of the Society for Epidemiologic Research in Edmonton, Canada (10). Through these avenues, potential study participants can become aware of the study and connect to our website. There are plans to "advertise" the site on other listserv groups overtime.

When a potential study participant connects to the website (http://www.epi.umn.edu/health_survey/), they are greeted by an initial page that invites him or her to participate in the study in order to receive an individualized nutrient intake profile. This page has a single hypertext link that connects the person to our "consent form" page (http://www.epi.umn.edu/~health_survey/health_survey.htm). A copy of the "introductory" page and the consent form page is provided in Appendix 3. The participant is encouraged to read through the consent form, which describes what is expected of the participant, what the participant will receive in return, and potential risks and benefits, among other information.

The consent form page also provides hypertext links to several other parts of the website. A link titled "Background and Research Proposal" provides a full-text copy of the grant application that was funded. An "Information Server" link provides some information about various nutrients of interest, while a "Q & A" link connects to a forum for comments from participants. A link to the "Research Team" provides information about each of the people involved in the study, including connections to individual home pages, while "Other Internet Links" provides annotated hypertext links to selected nutrition- and health-related websites. Finally, a "Logos and Banners" link (or "Help Us Recruit" button) connects the person to logos and advertisement banners that the person can copy for use on his or her own website to promote our study.

Study Participation

Once the participant has read through the consent information, a graphic and hypertext link connects the participant to our registration pages. The first page to which the person connects is informational only; it suggests the person use at least Netscape v. 3.0 or Internet

Explorer v. 3.0. The webserver determines from this page what browser the person is in fact using, and tailors the questionnaires that the person may eventually connect to based on that information. Specifically, Netscape and Internet Explorer browser versions 3.0 and higher are able to read javascript without some common errors; thus, the questionnaire versions that individuals using such browsers connect to have some javascript logic checking built in. If the person is using an earlier version of these browsers or another browser, they will be connected to versions of the questionnaire that do not have the logic checking built in. Otherwise, what the person sees is identical regardless of the browser version that is used.

From this page, the person can link to the registration page, also provided in Appendix 3. This page is a secure page, in that any information submitted from this page (and any of our survey modules) is encrypted for transmission. This means that if it is intercepted enroute, it will not be interpretable. The person is required to check a box that acknowledges that he or she has read the consent information, then has to provide a username ("Bill" is given as an example) and an email address (for example, "president@whitehouse.gov"). When this information is submitted to our server, the person is then automatically connected to a page that outlines the modules that make up the survey. The person is free to either connect to the first module, consisting of basic demographic information, or to exit from our website.

If the person connects to the first questionnaire module and completes it, the participant can choose to submit the information to our server. If submitted, the computer will automatically feedback the responses the person has provided, providing an opportunity for the person to go back and edit his or her responses if there is an error. Once the responses are verified, the person can submit the information to our computer. Again, this information is encrypted for transmission. The person is then automatically connected to the next questionnaire module. Once again, the person can choose to exit our website, or continue filling out the questionnaire. This sequence is followed through the several questionnaire modules until the final questionnaire module is completed and submitted to our computer.

If the person chooses to exit the survey, he or she is able to return to the website at a later time and register as a returning participant. At that time, the computer verifies that the username and email address have been registered, and then connects the person to the next questionnaire module that the person is to fill out. In this way, no person needs to fill out the same set of questions more than once, and a participant does not need to stay connected to our website for longer than the few minutes that is required to fill out a module.

Among questionnaire items, there are only two that the participant is required to fill out. The first is the gender of the person, whether male or female. This response is required as we have created somewhat different medical history and reproductive history modules for males and females. For example, the female modules ask questions regarding age at menarche and menopause, number of pregnancies, breastfeeding practices, use of oral contraceptives, etc. The male modules ask about digital rectal exams for prostate cancer screening, symptoms associated with prostate problems, etc. If a person is female, she will not need to fill out or skip over the male-specific questions, and vice versa. The item that we ask for is birthdate. Both the sex and birthdate (from which we calculate age of the respondent) are used to provide age-sex specific

information regarding the recommended dietary allowances that accompany the individualized nutrient intake feedback.

When the participant first registers for the study, a separate datafile is created on our computer that is specific for that participant. As he or she submits each questionnaire module to us, the relevant data are placed into that participant-specific datafile. Once the person has submitted all the questionnaire modules to us, the data are transferred from the participant-specific datafile into a study master database. In addition, the food frequency information is linked automatically to a nutrient analysis program that calculates over 100 nutrients and other dietary factors based on the frequency of known food items submitted to the computer. The output from this program is also placed in the master datafile.

In addition, some of the information from the nutrient analysis program is transmitted back to the study participant in real time (several seconds). The participant thus receives individualized information about their dietary intake patterns regarding percent of calories from fat, saturated fat, carbohydrate, and protein; dietary cholesterol and fiber intake; and intake of calcium, iron, zinc, and several vitamins. Comparison values derived from US federal government publications or the National Academy of Sciences (11,12) are also provided; when appropriate, these are given as age and sex specific values (e.g., for the Recommended Dietary Allowances).

The data flow for the study is provided on pages 13 and 14. The figure on page 14 labeled "ECCS Data Flow" outlines the procedures noted above. The figure on page 13 labeled "ECCS Data Flow - Detail" indicates that the participant can submit data from each questionnaire module separately, until the all questionnaire modules are completed. At that point, the participant's data are transferred to the study database. Note that this figure also indicates that if someone has submitted some of the modules, but not all, a reminder email message is sent to that person every two weeks until the survey has been completed and all modules have been submitted.

Results and Discussion

To date, we have only initial results. The website was officially "launched" on June 6th, 1997. As of July 30th, or a little less than eight weeks later, we have had 580 individual respondents. Currently, the majority of them are women (about 78%), and about two-thirds are from US email addresses. We are in the midst of planning the validation substudy and designing the six-month follow-up questionnaire. We anticipate that we will demonstrate that the Internet can be used for conducted epidemiologic studies, and we anticipate seeking funding for future studies based on this work.

PROGRESS IN RELATIONSHIP TO STATEMENT OF WORK

The following relates the Statement of Work as provided in our proposal to accomplishments and plans at one year into the study. The task as proposed is provided in *italics*, and our accomplishments and plans are provided in annotation beneath the relevant task.

Generally, aside from delays in hiring and establishing the website, which pushed official launch of the website back approximately 5 months overall, the study is otherwise on schedule. Unfortunately, because of this loss of time up-front, we will have relatively short follow-up time for study participants through the end of the funding period. However, we should still have adequate information to determine follow-up rates and whether the such Internet-based epidemiologic studies are feasible.

Task 1. Months 1-6: *Development of a database and surveys that will allow collection of epidemiologic information related to diet and breast cancer risk factors on the Internet through the World Wide Web. Ensure that concerns related to confidentiality of information are addressed.*

These tasks have been accomplished; these were largely completed by Month 8 of the study, approximately two months behind schedule. Initial delay was a result of delay in hiring programming help until the beginning of fall quarter of the academic year (Month 3).

Implementation of a secure server was delayed for various technical reasons until month 11 of the study; these technical reasons were related primarily to the fact that our server has a VMS operating system, and only one software company (Purveyor) currently has web server software with secure encryption capabilities for this platform. Several of the uses that we wanted for to implement were novel applications for the Purveyor software (for example, providing feedback to the participant), and appropriate implementation needed to be worked out with both our onsite computer administrators and the staff at Purveyor.

Task 2. Months 3-6: *Pilot testing and refining of the survey and database procedures within the Division of Epidemiology.*

This pilot testing occurred during months 6 through 10, with invitation to the 300-plus employees of the Division of Epidemiology to connect to our then-insecure web server to pretest the questionnaires. Comments and feedback were received from several people, resulting in improvements and language changes in the surveys and other aspects of the website.

Task 3. Month 6: *Establishment of an Internet site with our survey on the World Wide Web.*

The website was officially launched on June 6, 1997 (in Month 12).

Task 4. Months 6-18: *Data collection from survey participants through the Internet.*

This is now ongoing. Aside from rudimentary demographic statistics, data have not yet been otherwise analyzed.

Task 5. Months 7-18: *Implementation of dietary questionnaire reliability studies.*

We are now planning the implementation of these reliability studies. We plan to commence data collection in September (month 15).

Task 6. Months 6-12: *Development and pilot testing of methods for conducting follow-up surveys on the World Wide Web.*

We are currently developing follow-up surveys and implementation methods

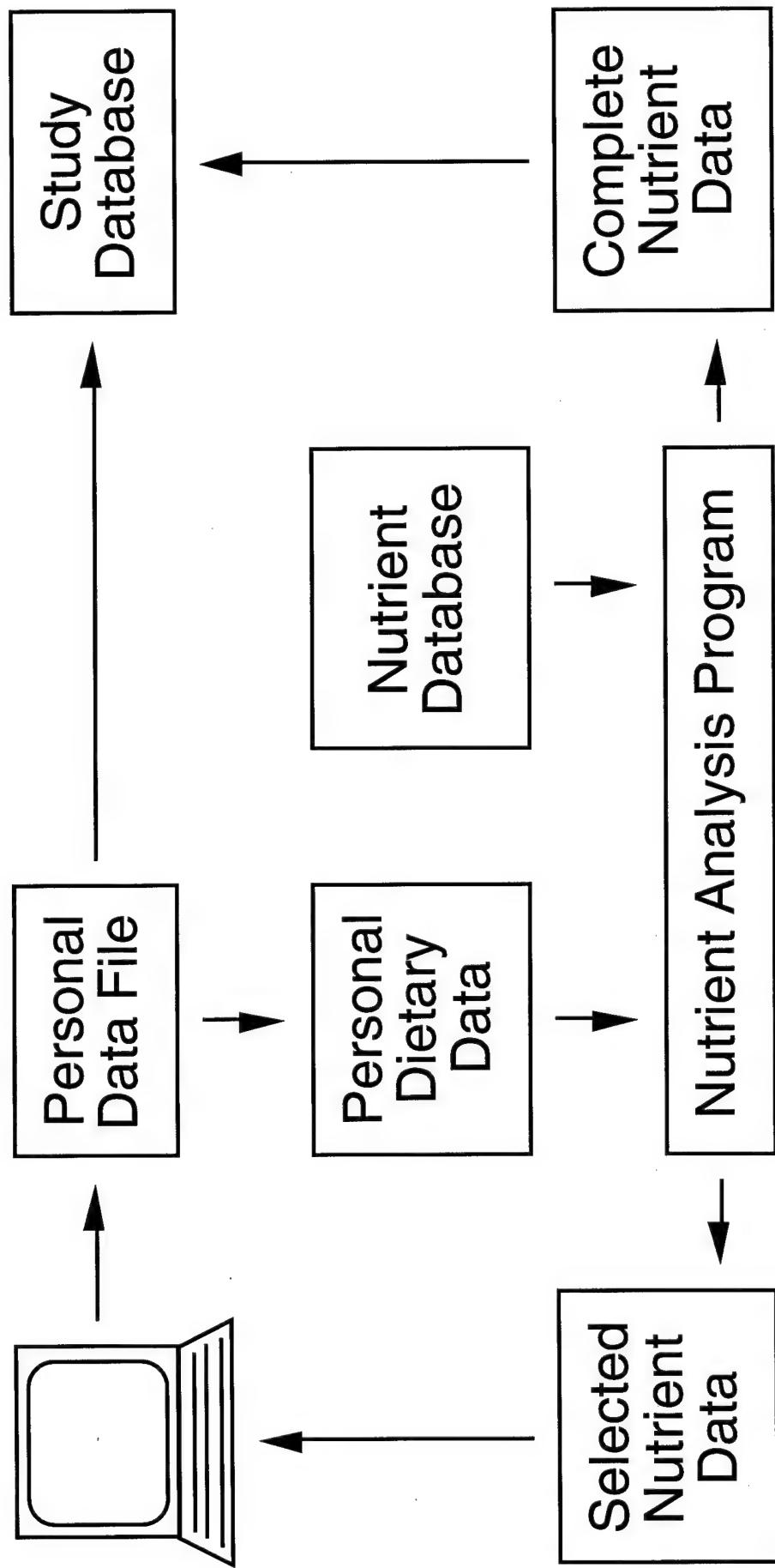
Task 7. Months 12-18: *Implementation of follow-up surveys on the World Wide Web.*

The follow-up surveys will be launched six months after the website was first launched (that is, on November 6th, 1997, in Month 17).

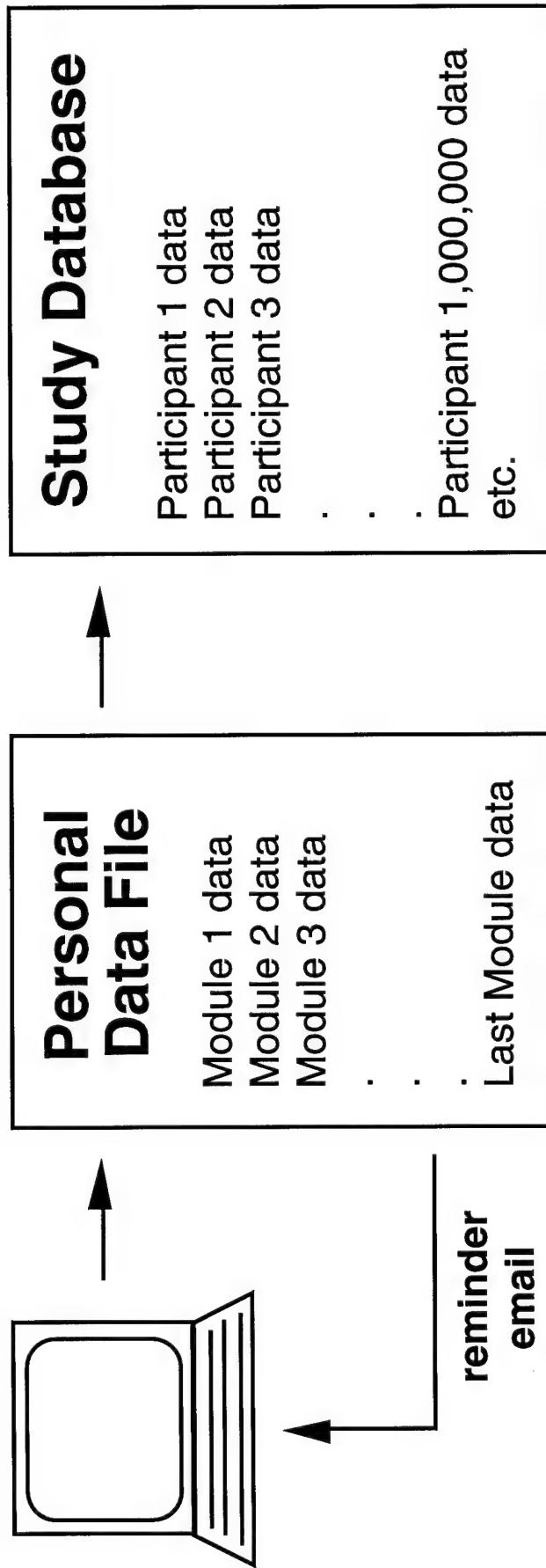
Recommendations

As we are in the midst of our study, and have only begun data collection, it is difficult to make recommendations concerning the conduct of studies such as this, the use of the Internet and related technologies for this work, or ultimately, insights into the relationship of diet and other risk factors to breast cancer. While the limited funding period for this IDEA grant ultimately precludes our ability to make inferences concerning the epidemiology of breast cancer, it is hoped that this project will have laid the foundation for new applications of Internet technology to the conduct of epidemiologic studies. Ultimately, with continued funding, we should be able to provide new insights into the etiology of breast cancer using such electronic World Wide Web-based surveys.

ECCS Data Flow



ECCS Data Flow - Detail



CONCLUSIONS

This feasibility study has already been a success in that it has demonstrated that it is possible to establish a website for the collection of dietary and other data. Initial indications are that data can be collected with minimal intervention on the part of study personnel once the website has been created, with appropriate programming to design the surveys, and to enable capture of the data by the webserver.

The website itself consists of a participant consent information page, with links to various other related information, including the registration page. Once the participant has registered, he or she is able to complete a series of questionnaire modules. Once these are completed, the participant's data is loaded into our study database, while the participant receives an individualized nutrient intake profile as an incentive for participation.

Plans are underway to implement a dietary validation study, comparing responses from the World Wide Web-based survey to a mailed questionnaire survey. This substudy will commence data collection in September, 1997. We are also designing a follow-up survey that will be made available to cohort members six months after they completed the baseline questionnaire, or for the earliest participants, in November, 1997.

Overall, the study appears to be progressing smoothly after the initial delays related to recruitment of appropriate personnel and some technical aspects concerning website design and establishment of a secure server. If this study successfully demonstrates the feasibility of conducting these types of epidemiologic surveys using the World Wide Web, it has the potential to usher in a new era of data collection technology for epidemiologic and population research.

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APPENDIX 1

STUDY QUESTIONNAIRE



QUESTIONNAIRE DEVELOPEMENT

Demographic Information

Lifestyle Questions

Fruit

Vegetables

Beverages

Breads, Cereals and Starches

Dairy Foods

Meats, Poultry, Fish & Eggs

Mixed Dishes & Vegetarian Items

Sweets, Snacks and Miscellaneous

Nutritional Supplements

Food Preparation

Female Medical History

Male Medical Questions

Female Reproductive History Questions

Male Reproductive History Questions

Family Medical History

Other Information

ECCSite! RSM

ECCSite Layout -CGI/ERX

|| MacHTTP System || Webmaster || Other ||

Demographic Information

Please enter your username:
[example:bill]

Please enter your email address:
[example:president@whitehouse.gov]

1. Please provide the following contact information. This will allow us to keep in contact as we update information in future months and years.

Name: First/Given: Middle:

Last/Family: Maiden:

Street Address:

City: State/Province:

Country: Zip/Postal Code:

E-mail address:

Telephone: Area Code Number

2. What is your date of birth? [ANSWER REQUIRED]

Month: Day: Year: 19

3. Are you male or female? female; male [ANSWER REQUIRED]

4. What is your race? Do you call yourself...

White

African American

Eskimo

Aleut

Asian or Pacific Islander

American Indian (specify tribe:)

If so, select which one:

If Other Asian or Pacific Islander, please specify:

22

Other race (specify:)

5. Are you of Spanish/Hispanic origin? Yes; No

If Yes, please specify:

If Other Spanish/Hispanic, specify:

6. In your own words, how do you describe your racial/ethnic identity?

7. In what U.S. state or foreign country were you and the following people born?

| | |
|----------------------|----------------------|
| You | <input type="text"/> |
| Your mother | <input type="text"/> |
| Your father | <input type="text"/> |
| Your mother's mother | <input type="text"/> |
| Your mother's father | <input type="text"/> |
| Your father's mother | <input type="text"/> |
| Your father's father | <input type="text"/> |

If you live in the United States, but were born in another country, continue with the next question. If you were born in the U.S. or do not live in the U.S., [click here](#) to jump to the next set of questions.

8. If you were born outside of the U.S. and you now live in the U.S., in what year did you come to the U.S. to stay?

I came to the U.S. to stay in the year 19 .

9. Do you speak a language other than English at home?

Yes.

No

Don't know

If you speak a language other than English at home, what is this language?

10. How well do you speak English?

Very well

Well

Not well

Not at all

Don't know

When you have finished this section, please press the "submit" button to send us the complete form. If you would like to change any responses, please do so before submitting this section.

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If you have any questions or comments about this survey, please e-mail us at:
healthsurvey@epihub.epi.umn.edu

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Questions or comments should be addressed to the [ECCSite! Webmaster](#)

URL: http://www.epi.umn.edu/health_survey/

Last Update: May 6, 1997

Lifestyle Factors

Please enter your username:
[example:bill]

Please enter your email address:
[example:president@whitehouse.gov]

Weight History

The following questions will help us develop a complete picture of your weight history. Some will ask for two different values for weight or height. Please fill in only the unit of measure you are most familiar with. For example, answer the first question stating your height **only** in feet and inches **or** centimeters.

1. What is your current height? (without shoes)

feet; inches; **OR** centimeters

2. What is your current weight? (without clothes, to the nearest pound or kilogram)

pounds; **OR** kilograms

3. Think back to when you were in 6th grade --or about the age of 12. Would you say at that time, compared to others your age, your weight was:

- below average for your age and height
- about average for your age and height
- above average for your age and height

4. Think back to when you were 18 years old --or about the time you graduated from high school. How much did you weigh when you were 18?

pounds; **OR** kilograms

5. How much did you weigh when you were 30 years old?

pounds; **OR** kilograms

I am younger than 30. [Click here](#) if you are younger than 30.

6. How much did you weigh when you were 40 years old?

pounds; OR kilograms

25

I am younger than 40. [Click here](#) if you are younger than 40.

7. How much did you weigh when you were 50 years old?

pounds; OR kilograms

I am younger than 50.

8. How much did you weigh one year ago? (to the nearest pound or kilogram)

pounds; OR kilograms

9. What is the most you have ever weighed?

pounds; OR kilograms

10. At what age did you weigh the most? (if female, not including pregnancy weight)

years old

11. Are you currently dieting to lose weight?

yes; no

12. How often do you diet to lose weight?

every day
every week
every month
every few months
about once a year or less
I never diet to lose weight.

13. Between the ages of 18-39, about how many times did you **intentionally lose** each of the following weights (please do not include weight loss after pregnancy or due to illness)? If you have never intentionally lost weight, please select zero for each category. If you have lost more than nine pounds, only count the amount of weight lost **once** per episode. For example, if you lost eleven pounds, select "one" after 10-19 pounds then fill in zero for 5-9 pounds as well as 20-49 and >50 pounds.

5-9 pounds (2.3-4.1 kg) : times

10-19 pounds (4.6-8.6 kg) : times

20-49 pounds (9.1-22.3 kg) : times

>50 pounds (>22.7 kg) : times

14. Between the ages of 18-39, about how many times did you lose the following weights 26
unintentionally? For example, weight loss due to illness.

| | |
|---|----------------------------|
| <input type="checkbox"/> 5-9 pounds (2.3-4.1 kg) : | <input type="text"/> times |
| <input type="checkbox"/> 10-19 pounds (4.6-8.6 kg) : | <input type="text"/> times |
| <input type="checkbox"/> 20-49 pounds (9.1-22.3 kg) : | <input type="text"/> times |
| <input type="checkbox"/> >50 pounds (>22.7 kg) : | <input type="text"/> times |

[Click here](#) if you are younger than 40.

15. Between the ages of 40-54, about how many times did you **intentionally lose** each of the following weights (please do not include weight loss after pregnancy or due to illness)?

| | |
|---|----------------------------|
| <input type="checkbox"/> 5-9 pounds (2.3-4.1 kg) : | <input type="text"/> times |
| <input type="checkbox"/> 10-19 pounds (4.6-8.6 kg) : | <input type="text"/> times |
| <input type="checkbox"/> 20-49 pounds (9.1-22.3 kg) : | <input type="text"/> times |
| <input type="checkbox"/> >50 pounds (>22.7 kg) : | <input type="text"/> times |

16. Between the ages of 40-54, about how many times did you lose the following weights **unintentionally?** For example, weight loss due to illness.

| | |
|---|----------------------------|
| <input type="checkbox"/> 5-9 pounds (2.3-4.1 kg) : | <input type="text"/> times |
| <input type="checkbox"/> 10-19 pounds (4.6-8.6 kg) : | <input type="text"/> times |
| <input type="checkbox"/> 20-49 pounds (9.1-22.3 kg) : | <input type="text"/> times |
| <input type="checkbox"/> >50 pounds (>22.7 kg) : | <input type="text"/> times |

[Click here](#) if you are younger than 55.

17. Between the age of 55 and now, about how many times did you **intentionally lose** each of the following weights (please do not include weight loss due to illness)?

| | |
|---|----------------------------|
| <input type="checkbox"/> 5-9 pounds (2.3-4.1 kg) : | <input type="text"/> times |
| <input type="checkbox"/> 10-19 pounds (4.6-8.6 kg) : | <input type="text"/> times |
| <input type="checkbox"/> 20-49 pounds (9.1-22.3 kg) : | <input type="text"/> times |

>50 pounds (>22.7 kg) : times

18. Between the age of 55 and now, about how many times did you lose the following weights **unintentionally**? For example, weight loss due to illness.

5-9 pounds (2.3-4.1 kg) : times

10-19 pounds (4.6-8.6 kg) : times

20-49 pounds (9.1-22.3 kg) : times

>50 pounds (>22.7 kg) : times

19. Do you follow a special diet?

yes no

20. If yes, what type of diet do you follow? Select all that apply.

weight loss
weight gain
diabetic
low cholesterol/low fat
low salt
vegan
vegetarian
macrobiotic
renal
other

If you chose "other," please tell us what type of diet you follow:

Smoking and Tobacco Use

The next set of questions asks about your smoking habits. If you have **never** smoked cigarettes, pipes, cigars **or** used snuff, [click here to jump to the next set of questions](#).

1. Have you smoked more than 100 cigarettes in your life? yes; no

[Click here](#) if you have never smoked cigarettes but have smoked pipes, cigars or used tobacco

a) About how old were you when you started to smoke cigarettes?

b) Do you smoke cigarettes now? yes; no

28

c) How old were you when you stopped smoking cigarettes?

d) During the time you smoked, about how many cigarettes did you smoke per day?

2. Have you ever smoked cigars? yes; no

[Click here](#) if you have never smoked cigars but have smoked pipes or used tobacco

a) About how old were you when you started to smoke cigars?

b) Do you smoke cigars now? yes; no

c) How old were you when you stopped smoking cigars?

d) During the time you smoked, about how many cigars did you smoke per day?

3. Have you ever smoked a pipe? yes; no

[Click here](#) if you have never smoked a pipe but have used tobacco

a) About how old were you when you started to smoke a pipe?

b) Do you smoke a pipe now? yes; no

c) How old were you when you stopped smoking a pipe?

d) During the time you smoked, about how many pipes did you smoke per day?

4. Have you ever chewed tobacco? yes; no

[Click here](#) if you have never chewed tobacco but have used snuff.

a) About how old were you when you started to chew tobacco?

b) Do you chew tobacco now? yes; no

c) How old were you when you stopped chewing tobacco?

d) During the time you chewed tobacco, about how many pouches did you chew per day?

5. Have you ever used snuff? yes; no

[Click here if you have never used snuff.](#)

29

a) About how old were you when you started to use snuff?

b) Do you use snuff now? yes; no

c) How old were you when you stopped using snuff?

d) During the time you used snuff, about how many cans did you chew per day?

6. Did anyone you lived with **during your childhood** smoke cigarettes, cigars or pipes? Please select all that apply.

father
mother
legal guardian
other relative or friend living in your house for at least one year
no one smoked in the house where I grew up

7. Did any of the following people you lived with **during your adult years** (age 18 or older) smoke cigarettes, cigars or pipes? Please select all that apply.

father
mother
legal guardian
spouse
other relative or friend living in your house for at least one year
no one smoked in the house where I lived as an adult

Physical Activity and Exercise

1. Do you participate in any activity (on a daily basis) that helps keep you physically fit?

yes; no

2. In the past year, how often did you take part in **mild** physical activity (such as golf, easy walking, fishing)?

times per day; per week; per month

For how many months in the past year did you participate in this activity?
 months

3. In the past year, how often did you take part in **moderate** physical activity (such as tennis, volleyball, alpine skiing, fast walking)?

times per day; per week; per month

For how many months in the past year did you participate in this activity?
 months

4. In the past year, how often did you take part in **vigorous** physical activity (such as jogging, vigorous swimming, soccer, strenuous sports)?

times per day; per week; per month

For how many months in the past year did you participate in this activity?
 months

5. Thinking about a seven day period (a week), how often did you participate in any regular activity long enough to work up a sweat in the past year?

often
sometimes
never/rarely

6. How often did you participate in moderate physical activity (such as tennis, volleyball, alpine skiing, fast walking) when you were the following ages? Please fill in the average number of hours you participated in the activity **per week** during the months you did those activities, then the average number of **months** per year.

a) During high school: hours per week for months per year

b) Between ages 18 and 24: hours per week for months per year

c) Between ages 25 and 34: hours per week for months per year

d) Between ages 35 and 44: hours per week for months per year

e) Between ages 45 and 54: hours per week for months per year

7. How often did you participate in strenuous physical activity (such as jogging, vigorous swimming, soccer, strenuous sports) when you were the following ages? Please fill in the average number of hours you participated in the activity **per week** during the months you did those activities, then the average number of **months** per year.

a) During high school: hours per week for months per year

b) Between ages 18 and 24: hours per week for months per year

c) Between ages 25 and 34: hours per week for months per year

d) Between ages 35 and 44: hours per week for months per year 31

e) Between ages 45 and 54: hours per week for months per year

8. Are you currently employed?

- yes, full time
- yes, part time
- I am not employed

If you are not currently employed, [click here](#) then submit this section.

9. How much time do you spend sitting when you are working?

- almost all the time
- more than half the time
- about half the time
- less than half the time
- almost never

10. How much time do you spend walking when you are at work?

- almost all the time
- more than half the time
- about half the time
- less than half the time
- almost never

11. How far do you walk going to and from your job?

blocks OR miles OR kilometers

12. What type of transportation do you usually use to get to your job?

- public transportation
- car
- bicycle
- walk

13. How often do you have to lift heavy weight or carry heavy things on the job?

- frequently
- sometimes
- very infrequently or never

When you have finished this section, please press the "submit" button to send us the complete form. If you would like to change any responses, please do so before submitting this section.

Vegetables

Please enter your username:
[example:bill]

Please enter your email address:
[example:president@whitehouse.gov]

For each food listed below, please enter how often **on average** you eat each item. You will need to enter the number of times you eat the food followed by whether you eat it on a daily, weekly, monthly or yearly basis. Use the past 12 months as a guide for your food intake.

1. Tomatoes (1) :

times per day; per week; per month; per year
 I don't eat tomatoes.

2. Tomato juice (small glass):

times per day; per week; per month; per year
 I don't drink tomato juice.

3. Tomato sauce, spaghetti sauce (1/2 cup or 128 g):

times per day; per week; per month; per year
 I don't eat tomato or spaghetti sauce.

4. Red chili sauce, taco sauce, salsa picante (1 tablespoon or 15 g):

times per day; per week; per month; per year
 I don't use red chili sauce, taco sauce or salsa picante.

5. String beans, green beans (1/2 cup or 68 g):

times per day; per week; per month; per year;
 I don't eat string beans or green beans.

6. Peas (1/2 cup or 80 g):

I don't eat peas.

7. Corn (1/2 cup or 80 g):

times per day; per week; per month; per year

I don't eat corn.

8. Beans or lentils - baked or dried (1/2 cup or 130 g):

times per day; per week; per month; per year

I don't eat beans or lentils.

9. Yellow or winter squash (1/2 cup or 103 g):

times per day; per week; per month; per year

I don't eat yellow or winter squash.

10. Eggplant, zucchini or other summer squash (1/2 cup or 90 g):

times per day; per week; per month; per year

I don't eat eggplant, zucchini or other summer squash.

11. Sweet potatoes, yams (1/2 cup or 70 g):

times per day; per week; per month; per year

I don't eat sweet potatoes .

12. Broccoli (1/2 cup or 78 g):

times per day; per week; per month; per year

I don't eat broccoli.

13. Cauliflower or brussel sprouts (1/2 cup or 62 g):

times per day; per week; per month; per year

I don't eat cauliflower or brussel sprouts.

14. Carrots (1/2 cup or 78 g):

times per day; per week; per month; per year

I don't eat carrots.

34

15. Cole slaw, cabbage, sauerkraut (1/2 cup or 75 g):

times per day; per week; per month; per year

I don't eat cole slaw, cabbage or sauerkraut.

16. Raw spinach (1 cup or 112 g):

times per day; per week; per month; per year

I don't eat raw spinach.

17. Cooked spinach (1/2 cup or 90 g):

times per day; per week; per month; per year

I don't eat cooked spinach.

18. Mustard greens, turnip greens, collards (1/2 cup or 88 g):

times per day; per week; per month; per year

I don't eat mustard greens, turnip greens or collards.

19. Iceberg or head lettuce (1 cup or 56 g):

times per day; per week; per month; per year

I don't eat iceberg or head lettuce.

20. Romaine or leaf lettuce (1 cup or 56 g):

times per day; per week; per month; per year

I don't eat romaine or leaf lettuce.

21. Celery (4" stick or 10 cm stick):

times per day; per week; per month; per year

I don't eat celery.

22. Mushrooms - fresh, cooked or canned (one):

times per day; per week; per month; per year

I don't eat mushrooms.

23. Beets (1/2 cup or 85 g):

35

times per day; per week; per month; per year

I don't eat beets.

24. Alfalfa sprouts (1/2 cup or 17 g):

times per day; per week; per month; per year

I don't eat alfalfa sprouts.

25. Garlic - fresh or powdered (1 clove or shake):

times per day; per week; per month; per year

I don't use garlic.

26. Onions (1 tablespoon):

times per day; per week; per month; per year

I don't eat onions.

27. Green or chili peppers (1/4 cup or 40 g):

times per day; per week; per month; per year

I don't eat green or chili peppers.

28. Overall, how often do you eat vegetables that are purchased fresh?

times per day; per week; per month; per year

I don't eat fresh vegetables.

29. Overall, how often do you eat vegetables that are purchased frozen?

times per day; per week; per month; per year

I don't eat frozen vegetables.

30. Overall, how often do you eat vegetables that are purchased canned?

times per day; per week; per month; per year

I don't eat canned vegetables.

31. Overall, how often do you eat vegetables that are grown organically (without the use of pesticides, herbicides or other chemicals)?

I don't eat organically grown vegetables.

32. If there are any other vegetables not included in our list that you eat regularly (at least once a week) please provide us with the following information about them:

Type of vegetable:

Amount you usually eat:

How often you eat it: times per day; per week

Type of vegetable:

Amount you usually eat:

How often you eat it: times per day; per week

Type of vegetable:

Amount you usually eat:

How often you eat it: times per day; per week

When you have finished this section, please press the "submit" button to send us the complete form. If you would like to change any responses, please do so before submitting this section.

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Reproductive History

Please enter your username:
[example:bill]

Please enter your email address:
[example:president@whitehouse.gov]

The following questions ask about your reproductive history. Please answer them to the best of your ability.

1. Have you ever menstruated? (Have you ever had a period?)

yes
 no If no, [click here](#) to skip to the next set of questions.

2. At what age did you begin menstruating? (What age did you have your first period?)

years old

3. When you menstruate(d), is (was) your cycle:

always regular
 usually regular
 never regular

4. When you menstruate(d), how many days are (were) there between the first day of one period to the first day of your next period?

days

5. Do you currently have menstrual periods?

yes If yes, [click here](#) to skip to the next set of questions
 no

6. If you answered "no" to the previous question, how old were you when you had your last menstrual period?

years old

7. What was the reason your menstrual cycle stopped?

natural menopause (the change of life)
 because of a hysterectomy (uterus surgically removed)
 because of a hysterectomy with oophorectomy (uterus and ovaries were

surgically removed)

took medication or had radiation that stopped my period

other; If other, specify reason:

38

Pregnancy and Breastfeeding

The following questions refer to each time you were pregnant. Please fill in information for each pregnancy, regardless of its outcome.

1. First, record your age at the **beginning** of each pregnancy
2. Next, record the number of weeks you were pregnant
3. Then, record the pregnancy outcome from the following categories:

- Currently pregnant
- Single live birth
- Multiple live birth, all lived
- Multiple birth, one stillborn (one child born dead after five months or more of pregnancy)
- Multiple birth, all stillborn (all children born dead after five months or more of pregnancy)
- Stillbirth (child born dead after five months or more of pregnancy)
- Miscarriage (spontaneous loss of child before five months)
- Ectopic pregnancy
- Induced abortion
- Other

4. Next, if the pregnancy resulted in a live birth, indicate whether you breastfed and how many months you breastfed the child.

If you have never been pregnant, check "no" to the first question then click the button next to it to skip to the next set of questions.

1. Have you ever been pregnant? (please include current pregnancy, live births, stillbirths, miscarriages, ectopic pregnancies and induced abortions.)

yes

no [click here](#) to go to the next set of questions

2. If yes, how many times have you been pregnant?

times

Please provide the following information for each of your pregnancies:

1. Pregnancy #1

- How old were you at the beginning of your first pregnancy?

years old

How many weeks were you pregnant?

39

weeks

What was the outcome of this pregnancy?

If this pregnancy resulted in a live birth, did you breastfeed after this pregnancy?

yes; no

For how long did you breastfeed? weeks **OR** months

[Click here](#) if this was your last pregnancy.

2. Pregnancy #2

How old were you at the beginning of your second pregnancy?

years old

How many weeks were you pregnant?

weeks

What was the outcome of this pregnancy?

If this pregnancy resulted in a live birth, did you breastfeed after this pregnancy?

yes; no

For how long did you breastfeed? weeks **OR** months

[Click here](#) if this was your last pregnancy

3. Pregnancy #3

How old were you at the beginning of your third pregnancy?

years old

How many weeks were you pregnant?

weeks

What was the outcome of this pregnancy?

40

If this pregnancy resulted in a live birth, did you breastfeed after this pregnancy?

yes; no

For how long did you breastfeed? weeks **OR** months

[Click here](#) if this was your last pregnancy

4. Pregnancy #4

How old were you at the beginning of your fourth pregnancy?

years old

How many weeks were you pregnant?

weeks

What was the outcome of this pregnancy?

If this pregnancy resulted in a live birth, did you breastfeed after this pregnancy?

yes; no

For how long did you breastfeed? weeks **OR** months

[Click here](#) if this was your last pregnancy

5. Pregnancy #5

How old were you at the beginning of your fifth pregnancy?

years old

How many weeks were you pregnant?

weeks

What was the outcome of this pregnancy?

If this pregnancy resulted in a live birth, did you breastfeed after this pregnancy?

yes; no

For how long did you breastfeed? weeks **OR** months

41

[Click here](#) if this was your last pregnancy

6. Pregnancy #6

How old were you at the beginning of your sixth pregnancy?

years old

How many weeks were you pregnant?

weeks

What was the outcome of this pregnancy?

If this pregnancy resulted in a live birth, did you breastfeed after this pregnancy?

yes; no

For how long did you breastfeed? weeks **OR** months

[Click here](#) if this was your last pregnancy

7. Pregnancy #7

How old were you at the beginning of your seventh pregnancy?

years old

How many weeks were you pregnant?

weeks

What was the outcome of this pregnancy?

If this pregnancy resulted in a live birth, did you breastfeed after this pregnancy?

yes; no

For how long did you breastfeed? weeks **OR** months

[Click here](#) if this was your last pregnancy

8. Pregnancy #8

How old were you at the beginning of your eighth pregnancy?

42

years old

How many weeks were you pregnant?

weeks

What was the outcome of this pregnancy?

If this pregnancy resulted in a live birth, did you breastfeed after this pregnancy?

yes; no

For how long did you breastfeed? weeks **OR** months

[Click here](#) if this was your last pregnancy

9. Pregnancy #9

How old were you at the beginning of your ninth pregnancy?

years old

How many weeks were you pregnant?

weeks

What was the outcome of this pregnancy?

If this pregnancy resulted in a live birth, did you breastfeed after this pregnancy?

yes; no

For how long did you breastfeed? weeks **OR** months

[Click here](#) if this was your last pregnancy

10. Pregnancy #10

How old were you at the beginning of your tenth pregnancy?

years old

How many weeks were you pregnant?

weeks

43

What was the outcome of this pregnancy?

If this pregnancy resulted in a live birth, did you breastfeed after this pregnancy?

yes; no

For how long did you breastfeed? weeks **OR** months

11. How many girls and boys have you given birth to? (include only live births):

girls; boys

12. Did you ever try for one straight year or more to become pregnant without success?

yes; no

13. Did you or your partner ever visit a doctor, clinic, or hospital because you had a problem getting pregnant?

yes; no

14. What was the reason you had difficulty becoming pregnant?

problem with ovaries
problem with fallopian tubes
problem with uterus/cervix
husband had fertility problem
other fertility problem
no problem was found
not sure

15. Has a doctor ever prescribed medication to help you become pregnant?

yes; no

If yes, what was the name of the medication?

How long did you take the above medication?

16. Did you ever have infertility surgery or any other procedures in an attempt to become pregnant?

yes; no

If yes, which of the following procedures did you have? Select **all** that apply. Please note that the way you are able to select more than one option will differ based on the type of computer you are using.

Birth Control

1. Have you ever taken birth control pills for any reason?

yes, currently taking

yes, but not currently taking

no [Click here](#) if you have never taken birth control pills.

not sure

2. How old were you when you starting taking birth control pills?

years old.

3. How old were you when you stopped taking birth control pills?

years old.

I am currently using birth control pills.

4. The following table asks for information about birth control pill use.

- Select the brand name of the birth control pills you have taken, the dose of the pills you took, how long you took them, and at what age you started using them. If you took the pill intermittently (have stopped using the pill, then started using at a later date) count each time you have taken the pill separately.
- If you have taken more than one type of birth control pill, please provide us with information for each type.
- If the specific birth control pill you have taken is not in our list, please provide us with the appropriate information in the questions after the table.
- If you are unsure of the type of birth control pill you use(d), [click here](#) to see photographs of commonly used pills (link not yet active.)
- If you don't remember the name or dose of the birth control pill you took, just fill in the information about how long you took it.

| Name of Birth Control Pill | Dose | How Long Taken | Age |
|----------------------------|----------------------|----------------------|----------------------|
| <input type="text"/> | <input type="text"/> | <input type="text"/> | <input type="text"/> |
| <input type="text"/> | <input type="text"/> | <input type="text"/> | <input type="text"/> |
| <input type="text"/> | <input type="text"/> | <input type="text"/> | <input type="text"/> |
| <input type="text"/> | <input type="text"/> | <input type="text"/> | <input type="text"/> |
| <input type="text"/> | <input type="text"/> | <input type="text"/> | <input type="text"/> |

If you have taken more than five different birth control pills, please tell us how many: 45

If the specific brand name of the oral contraceptive you take is not included in our list, please tell us about it:

- Name of oral contraceptive: _____
- Dose you took: _____
- How long you took it: _____

- Name of oral contraceptive: _____
- Dose you took: _____
- How long you took it: _____

5. Have you ever used birth control methods other than oral contraceptives?

yes

no [Click here](#) if you have never used birth control.

not sure

6. The following table asks for information about birth control methods **other than oral contraceptives**.

- Select the method of birth control you used.
- Next, tell us how long you used this method.
- If you have used more than one method of birth control, please provide us with information for each type.
- If the specific birth control method you used is not on our list, please provide us with the appropriate information in the questions after the table.

| Name of Birth Control Method | How Long Used |
|------------------------------|---------------|
| | |
| | |
| | |
| | |
| | |
| | |

If you have used more than five different methods of birth control, please tell us how many:

If the specific type of birth control you used is not on our list, please tell us about it:

- Name of method: _____

How long you used it:

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Name of method:

How long you used it:

When you have finished this section, please press the "submit" button to send us the complete form. If you would like to change any responses, please do so before submitting this section.

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URL: http://www.epi.umn.edu/health_survey/

Last Update: May 6, 1997

Other Information

Please enter your username:
[example:bill]

Please enter your email address:
[example:president@whitehouse.gov]

Congratulations!

You are almost finished. Before you leave, please take a few more minutes to provide us with some additional information about yourself.

1. What is your marital status?

- Now married
- Living together with a partner
- Widowed
- Divorced
- Separated
- Never married

2. How frequently do you participate in organized religious or spiritual activities?

- More than once a week
- Every week
- Regularly, but not every week
- Only on special occasions
- Never
- Don't know

3. How often do you attend religious or spiritual services at a church, mosque, temple, or other religious or spiritual meeting place?

4. What is your present religious or spiritual affiliation? Select all that apply.

- Christian
- Buddhist
- Hindu
- Islam
- Judaism
- Shinto
- Wiccan

— Santeria, Voodou, or Condelembe
Pagan or other earth-centered religion
Atheist
Agnostic
Don't know
Other (please specify)

48

5. What is the religion or spiritual tradition in which you were raised? Select all that apply.

Christian
Buddhist
Hindu
Islam
Judaism
Shinto
Wiccan
Santeria, Voodou, or Condelembe
Pagan or other earth-centered religion
Atheist
Agnostic
Don't know
Other (please specify)

6. What is the highest level of school you completed?

7. What is your current employment status? Select all that apply.

employed full-time
employed part-time
volunteer full-time
volunteer part-time
homemaker
retired
unemployed
student
disabled, unable to work
other; Please specify:

8. What has been your usual job or occupation - the one you have worked at the longest? For example, carpenter, nurse, waitress, sales associate.

9. What is your yearly household income in U.S. Dollars?

10. During the past five years, did you have any health care insurance?

yes
no
not sure

49

If yes, please tell us what kind of insurance: _____

11. What is your social security number? Keep in mind that this information is optional. No one will have access to this number except the research team at the University of Minnesota. We will only use your social security number to search death certificates if we've lost contact with you.

_____ - _____ - _____

12. Please provide the following information about a relative or friend who will always know your whereabouts.

Name: First/Given: _____ Middle: _____

Last/Family: _____

Street Address: _____

City: _____ State/Province: _____

Country: _____ Zip/Postal Code: _____

E-mail address: _____

Telephone: Area Code _____ Number _____

13. Please tell us how the above person is related to you (for example, your brother or a close friend.)

14. In the future, we may want to obtain a blood sample from you to look at genetic and physiologic factors. If so, we would ask for your specific consent and provide you with materials for your doctor to draw the blood sample. Generally speaking, are you willing to provide us with a blood sample?

yes
no
don't know

15. We may want to obtain a copy of your medical records to look at details of any diseases you may report. If so, we would provide you with a specific consent form for that purpose. Generally speaking, are you willing to give us permission to access your medical records?

yes
no
don't know

50

16. We may want to send you a questionnaire by regular mail. Are you willing to be contacted by regular (snail) mail?

yes
no
don't know

When you have finished this section, please press the "submit" button to send us the complete form. If you would like to change any responses, please do so before submitting this section.

|| [Top of Page](#) || [Go to our home page](#) ||

If you have any questions or comments about this survey, please e-mail us at:
healthsurvey@epihub.epi.umn.edu

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|| [Q & A](#) || [Research Team](#) || [Other Internet Links](#) || [Front Page](#) ||

Please note: If certain features don't seem to be working, you should download the new JavaScript-enabled Netscape Navigator 3.0.

Questions or comments should be addressed to the [ECCSite! Webmaster](#)

URL: http://www.epi.umn.edu/health_survey/

Last Update: May 6, 1997

APPENDIX 2

STUDY PUBLICITY

From: "Larry Kushi" <Kushi>
Date: Fri, Jun 6, 1997 11:00 AM
To: martinson rightmyer yochum finnegan vachon
Subject: TEXT for ADVERTISEMENTS

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PARTICIPATE IN ONE OF THE FIRST EPIDEMIOLOGIC FOLLOW-UP STUDIES
ON THE WORLD WIDE WEB

Link to: http://www.epi.umn.edu/health_survey/

Investigators at the University of Minnesota School of Public Health in Minneapolis, Minnesota, USA, are carrying out one of the first research studies to use the Internet to look at relationships between what people eat and their long-term health. You can be a part of this study! Register and Participate at ECCSite!, Website of the Epidemiologic Cyberspace Cohort Study (URL: http://www.epi.umn.edu/health_survey/).

In return for your participation, you will receive your own personalized nutrient intake profile and periodic study updates. We're hoping for thousands, if not millions of participants. Join us in this great adventure to see if we can use the Internet to conduct large-scale epidemiologic follow-up studies.

With thanks in advance, and apologies for cross-postings.

The ECCSite! Research Team
healthsurvey@epivax.epi.umn.edu

P.S. Please pass this message on to anyone you think may be interested in participating in this study.

* JOIN OUR WWW EPIDEMIOLOGIC COHORT STUDY OF DIET AND HEALTH AT *
* http://www.epi.umn.edu/~health_survey/health_survey.htm *
* ----- *
* Lawrence H. Kushi, Sc.D. email: kushi@epivax.epi.umn.edu *
* Division of Epidemiology telephone: 612-626-8578 *
* Univ of Minnesota School of Public Health FAX: 612-624-0315 *
* http://www.epi.umn.edu/~health_survey/personal/kushi/lhkhomepage.html *

Epidemiology Monitor

A monthly update covering people, events, research and key developments

Minnesota Investigators Are Exploring the Use of the Internet for Conducting Followup Surveys

Last March we ran a story on the use of the Internet to study ski injuries. Now another effort to explore the use of the Internet has surfaced called the Epidemiologic Cyberspace Cohort Study: A Longitudinal Survey of Diet, Lifestyle, and Health. The rationale for the cancer study, according to its designers Larry Kushi and John Finnegan, lies primarily in the potential of the Internet to provide inexpensive, highly-efficient data collection and followup of large numbers of individuals. They suggest that just as email has come to complement regular mail, so too the Internet may provide a substitute under some circumstances for the mailed questionnaire in epidemiologic

studies. In contrast to the skier study that appeared to be a case-finding and incident-reporting study, according to Kushi, the Minnesota study is a more "classic" epidemiologic study, i.e., an attempt at a true cohort study.

To learn more about this pioneering effort, the *Epidemiology Monitor* questioned Kushi about some of the circumstances surrounding the initiation of this feasibility project. Here's what he told us:

EM: *How and why did you get the idea to do this feasibility study? There are lots of epidemiologists out there and the*

— *Internet study, continued on page 2*

SER President Highlights Problems With NIH Peer Review and Offers Suggestions for Change

How many epidemiologists does it take to change a light bulb? The answer is five. One to install the bulb and four to critique the methods.

This was the joke told by SER President Leslie Bernstein in opening her remarks to the audience gathered in Edmonton Alberta for the 30th annual Society for Epidemiologic Research meeting in mid-June. She may have been poking fun at epidemiologists but she had a more serious point in mind—namely that too much of a good thing (i.e. criticism), or at least too much of a good thing done poorly, can cause very

serious consequences for epidemiologists.

In wondering what topic to select for her SER address, Bernstein was influenced by the comments of National Breast Cancer Coalition members who asked her, "why are epidemiologists so incredibly critical of each other?" According to these members, many of whom are laypersons, epidemiologists are much more rigid and likely to be unsupportive of their colleagues' ideas than are scientists in other fields.

— *SER, continued on page 4*

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Epi Research

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NOTICE!

The next issue you receive, in early September, will be a combined August/September issue

JULY
1997

VOLUME
EIGHTEEN
NUMBER
SEVEN

Internet study, continued from page 1

Net has been around for awhile. Assuming there have not been other attempts at this, why are you among the first?

“...When I started to appreciate the forms-based capabilities of HTML..., a light bulb went off: Here was a way to collect information in a reasonably structured format, with direct data entry by the participant, and direct download into a local database...”

Kushi: I don't know if we are truly the first. The only other epi-oriented study that I am aware of is the skier incident survey that you highlighted in a recent issue. Regarding the genesis of our study, some of us here had early on thought about trying to use the Internet in epidemiologic research applications. Our initial ruminations on the idea occurred when email was becoming much more widespread, during the dark ages before the WWW (say, four years ago ...). We thought about the possibilities of using email to collect information - indeed, there have been many such brief surveys that I have seen. Simple examples include everything from surveys to examine among campus colleagues the best times to hold seminars, to more structured and somewhat lengthier questionnaires about PC usage, or other topics. However, we decided that email-based surveys, because of their lack of ability to format the questions and responses, would likely be as labor intensive as standard methods for collecting information (structured interviews, CATI, mailed questionnaires, etc.). With the development of the WWW, Netscape and Mosaic, and a de facto HTML standard for making information available on the Internet, we started to think about the possibilities of using the Internet for epi research applications once again. When I started to appreciate the forms-based capabilities of HTML, and the ability to have people submit information to one's server, a light bulb went off: Here was a way to collect information in a reasonably structured format, with direct data entry by the participant, and direct download into a local database. If this could

work, it would be a highly efficient and inexpensive way to collect information from potentially large numbers of individuals.

Regarding specific types of research applications, it seemed right up front that we couldn't really do a “population-based” survey of Internet users, since there is really no easy way to determine what proportion of the population has WWW access, or what their overall demographic profiles are like. Common concerns that were raised at SER were “what's the sampling frame?” and, “Selection Bias!” If we were to try to characterize the WWW population as a whole, then admittedly, there would be concerns.

However, we thought instead that a much more logical application of the Internet would be to try to establish a WWW-based cohort that we could then follow forward in time. In this way, as long as follow-up rates were reasonable, the study could still be internally valid. If the demographic profile of the respondent population could be characterized, and range of exposures was sufficiently varied to enable investigation of associations of interest, then this could really be a great setting for efficient conduct of studies.

From there, we developed the relatively brief proposal that you can read at our website that we submitted to the U.S. Army's Breast Cancer Research Program, which funded us for two years (funding expires next summer). We also submitted a more detailed proposal on exactly the same topic, but with better development of the ideas we had at the time for the website, and also with a somewhat higher budget that would have allowed us to purchase our own independent server (we're piggy-backing on the U of M's

— *Internet study, continued on page 3*

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Internet study, continued from page 2

Division of Epi computer at this time), but the reviewers rated it in the "Lower Half" of applications. Their primary criticism, despite our clear title of the proposal as a "Feasibility" study, was that we didn't have any pilot data! That was the intent of the proposal. Of course, we hope that we will now have the relevant pilot data from this project to get more extended NIH funding for longer term follow-up.

EM: *What reactions did you get to your Internet approaches at SER?*

Kushi: As far as reactions, people were generally quite intrigued. I think most people have tended to think of the Internet as either strictly for information dissemination (such as information on Epidemiology Departments and academic programs for prospective students, to more creative applications such as distance learning, setting up virtual Schools of Public Health, or electronic journals), or as a nuisance that is more of a distraction from more serious work than a potential benefit. Only a few that I'm aware of have thought of the Internet the other way around - as a potential way of interacting with people out there, of collecting information. Note that this applies only to my very informal view of the Epi community, and may be a misrepresentation. I think there are lots of people in the business community who have thought about how to get people more actively involved in the WWW, so that they can find out information about them and find out how to market to them and get them to buy things over the Internet.

The major specific comments at SER had to do with "Selection Bias" and "generalizability" as noted previously, and with "confidentiality." Speaking of which, the development of encryption capabilities that the business world is now comfortable with (and the National Security Agency and the rest of the Federal Government is uncomfortable with because it hinders their ability to snoop), was the other piece that was required before we felt that we could

really conduct a web-based cohort study.

The more interesting comments through email since we've launched the site have led to some improvements/modifications (for example, ability to edit responses before submitting them to us - that should be in place soon, if not already), and related to the IRB approval process. One of the people who heard about it was interested in how we got approval.

EM: *Have you heard of others doing this yet?*

Kushi: I've not yet heard of others doing this, aside from the skier survey as I mentioned previously - and I heard about that from you. As you may be aware, in the March issue of *Epidemiology*, Ken Rothman basically proposes in an editorial that someone do a study such as what we're doing. He was not aware of our study at the time, and apparently, in an upcoming issue, the person doing the skier survey will have a letter published in response to that editorial. There have been other one-shot surveys that I've seen (for example, a survey of musculoskeletal injuries of organists, URL: <http://www.metronet.com/~organmed/>).

EM: *Do you have any early data on how it is going? As well, better, or less well than expected?*

Kushi: I'd say that it's going quite well given our relatively limited active promotion at this point. As of June 23, 1997, just over three weeks after we announced the site, we had 332 registrants, 95 male, 205 female, the rest have not filled out the demographic module yet. Of the first 100 participants to finish the survey, 78% are women and 22% men. Also, 68% are from the US and 32% from other countries. I would guess that the majority of early registrants are health researchers and practitioners, since that's where we initially announced the study. We would like to broaden the population beyond

“Only a few that I'm aware of have thought of the Internet the other way around - as a potential way of interacting with people out there, of collecting information...”

Internet study, continued from page 3

that, of course, but that's where we'll get initial constructive feedback as well.

EM: What are the potential advantages of doing a cohort study in this fashion?

Kushi: Regarding potential advantages, these are the obvious. In comparison to other large-scale prospective cohort studies, such as our Iowa Women's Health Study, or the Nurses' Health Study:

1. Much less cost - basically elimination of printing, postage, data entry costs.
2. Potential ability to update exposures or to ask about new information in a timely fashion once the cohort is established.
3. Ability to reach a potentially very broad audience. (As Rothman's editorial put it, the Internet population is "an epidemiologist's dream." We sent in a response that said that while we were optimistic that it was, we weren't ready to call it an epidemiologist's web dream yet.)
4. Ease of follow-up through email? This is a big unknown.

EM: What are the potential disadvantages of your study?

Kushi: The potential disadvantages include:

1. We are limited to collection of self-administered questionnaire information. We will have to have usual data collection methods for other information (e.g., obtaining written permission to access medical records, then getting copies of medical records for endpoint documentation). Ditto for collection of biological samples. Of course, this is a limitation of Nurses' Health Study-type cohorts as well.

2. What will the population really look like? Will the range of relevant exposures truly be informative, and can we expect reasonable numbers of endpoints to accrue in the cohort? For

example, as we wrote to Ken Rothman, if most of the respondents are college-aged male computer nerds, that would be a poor population for a study of postmenopausal breast cancer. Of course, I don't expect that to be the case.

3. Potential ability to enroll people throughout the world. While this is more a strength than a weakness, it does complicate issues such as appropriateness of the questionnaire for different populations, etc. For example, we ask several diet-related questions. A nutritionist in Australia emailed us about the fact that nutrient composition can vary considerably from country to country, given differences in fortification practices, foods that are consumed, etc.
4. Reliability and validity of information collected through the web, which is a grossly understudied topic.

Those are just off the top of my head. There may have been others we talked about in our proposal that I can't remember off hand.

Readers who wish to check out the site for the study may do so at:

http://www.epi.umn.edu/~health_survey/health_survey.htm ♦

SER, continued from page 4

study while being careful not to redesign the study.

5. Train our graduate students and post-docs to ensure that they understand the process, can compete, and that they know how to review.

Dr. Bernstein is professor of preventive medicine, senior associate dean for faculty affairs, and scientific director of the Cancer Surveillance Program at the University of Southern California School of Medicine in Los Angeles. ♦

Advantages to Web-based epidemiology studies:

- reduced cost
- timely updating
- access to a broad audience
- ease of followup (?)

Disadvantages to Web-based epidemiology studies:

- only self-administered questionnaire info is collected
- generalizability of the population/selection bias
- cultural differences among participants
 - questionable reliability and validity

APPENDIX 3

STUDY CONSENT FORM

Want to know how much fat you eat? How about cholesterol? Or calcium?



Receive an individualized nutrient intake profile! You can find out how much fat you eat, and how that compares with recommendations. We'll send you information about other nutrients too. All you have to do is participate in our study, the Epidemiologic Cyberspace Cohort Study, what we hope will be a long-term project to look at diet and lifestyle and how that relates to health.

Find out more about the study **NOW** by reading our participant consent information.

University of Minnesota

School of Public Health

Division of Epidemiology

ECCSite! *Website of the Epidemiologic Cyberspace Cohort Study*

University of Minnesota

School of Public Health

Division of Epidemiology

- [**Front Page**](#)
- [**Background**](#)
- [**Information**](#)
- [**Q & A - FAQ**](#)
- [**Our Team**](#)
- [**Other Links**](#)
- [**Help Us Recruit**](#)

The Epidemiologic Cyberspace Cohort Study:

A Longitudinal Survey of Diet, Lifestyle and Health



Welcome!

|| Returning participants please [sign-in](#) ||

|| New visitors please read the information below ||

Participant Consent Information

Please join our study!

We invite you to participate in our study to look at whether the Internet and the World Wide Web can be used to conduct epidemiologic studies of food, lifestyle and health.

What Do I Have To Do To Participate?

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After you register, we will ask you to **fill out some questionnaires**. They cover topics such as the foods you eat, your medical history, medications you may have used, your habits like exercise or smoking, and a weight history.

Six months after you complete these questionnaires, we will ask you to fill out a follow-up questionnaire. This follow-up will ask you to update some of your information.

If a large number of you (thousands! hundreds of thousands!) participate in this study, then in the long run, we will be able to look at relationships between the information you give us with the development of cancer and heart disease. We need your active participation!

What Do I Get For Participating?

We will send you **an individualized nutrient intake profile** that is based on your answers. You will also get a set of dietary recommendations based on your age, sex, and individual food intake.

We will also send you periodic updates of how our study is doing.

Once I Register, Do I Have to Fill Out Everything?

No. Participation is completely voluntary (as if we could somehow force you to fill out our questionnaires). If you don't register and don't participate, that is your choice, and we won't ever know about it. You can choose to fill out only a portion of the questionnaire or to not answer specific questions. Of course, there is no penalty for not answering questions.

You can also quit in between sections of the questionnaire and come back later to fill out the rest. When you register as a returning participant, you will be connected automatically to the next set of questions where you left off. That way, you won't have to fill out any sections twice.

By registering for the study, you will be consenting to participate in this research study.

How Much Time Will It Take?

It will take one to two hours to complete all the questions. You are free to skip any

questions that you don't want to answer! One exception is that we ask everyone to indicate what sex they are. That way, if you're male, you won't have to answer any questions about pregnancy and if you're female you won't be asked about your prostate!

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What About Privacy and Security?

This is not an anonymous survey. However, these questionnaires use the security enhancements provided by Netscape's SSL (Security Socket Layering). **You can be assured that your responses will be encrypted for transmission and won't be read by anyone other than the members of the research team at the University of Minnesota.**

Your name, address, and any other identifying information you give us will **never** be sold, given away, or provided to any other mailing list or person.

We will use identifying information (like your email address) only to maintain contact with you, and to link information that you provide on follow-up questionnaires to the first questionnaire you fill out. Of course, in any published report, we will not include any information that will make it possible to identify any person.

This study has been approved by the Institutional Review Board, Committee on the Use of Human Subjects in Research, University of Minnesota.

What Are the Downsides of Participating?

Aside from the time it takes to fill out the questionnaires, there are virtually no risks involved with participation in this study. However, if you feel that you have developed any problems as a result of participating, please contact the research staff at:

healthsurvey@epivax.epi.umn.edu

You can also contact us at this email address if you have any other questions about this study.

If you have any questions or concerns regarding this study and would like to talk to someone other than the researcher(s), please contact:

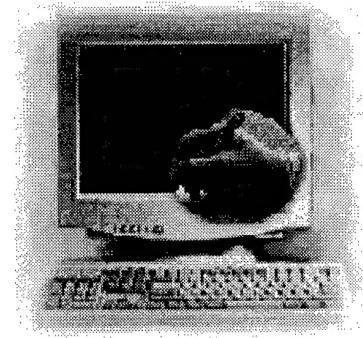
Hospital Patient Relations
2-499 Fairview University Medical Center
500 Harvard Street Southeast
Minneapolis, Minnesota 55455
Telephone: 612-626-5050

If you spend a lot of time in front of a computer, you might want to think about ergonomic issues. Check out this Office Ergonomics page for links to websites on this topic.

Who Funds This Study?

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This study is funded by a research grant from the Breast Cancer Research Program of the U.S. Army Medical Research & Materiel Command (USAMRMC).



|| [Sign-up for the study](#) ||

Menu

|| Returning Participant Sign-In ||

- If you are a returning participant and have previously registered with us, please sign-in and continue with your survey.

|| Background & Research Proposal ||

- Read about the background research and interests surrounding this survey, as well as a copy of the research proposal.

|| Information Server ||

- Visit our information server. An information resource for developing healthy eating habits, recipes, and proper nutrition.

|| Q & A ||

- Answers to your questions about nutrition and other health related subjects, as well as comments about this web site.

|| Research Team ||

- An in depth look at our survey and web site research team.

|| Other Internet Links ||

- A small collection of valuable internet sites related to diet and health.

|| Logos and Banners ||

- Help us recruit participants for our study! We have several logos and banners you can copy for your website or home page.

|| [Back to the Top](#) || [Participant Consent Information](#) || [Register](#) ||

|| 3888 visitors since Wednesday, June 25, 1997 13:26:33 ||

ECCSsite!

*Website of the Epidemiologic
Cyberspace Cohort Study*

University of Minnesota

School of Public Health

Division of Epidemiology

Registration Page

Epidemiologic Cyberspace Cohort Study

For the purpose of this study we require our visitors to enter an email address; the email address will allow us to contact you to fill out follow-up questionnaire. We also require that you actively consent to participate by clicking the appropriate box below. If you do not have an email address we are sorry, you may not participate. Despite this requirement, all are welcome to browse our informational server.

We have faith in our study participants, and know that we don't have to tell you to please fill out the questionnaires as accurately and completely as possible. Of course, you can voluntarily skip any items for which you don't want to provide information.

Thanks for your willingness to participate!

-ECCS Survey Team

Please enter a username:
[example:bill]

Please enter your email account:
[example:president@whitehouse.gov]

Please Check:

I have read the the foregoing participant consent information and understand it, and any questions which have occurred to me have been answered to my satisfaction. I understand that I may ask

[|| Back ||](#) [Background & Research Proposal](#) [|| Information Server ||](#)

[|| Q & A ||](#) [Research Team](#) [|| Other Internet Links ||](#) [|| Front Page ||](#)

Please note: If certain features don't seem to be working, you should download the new JavaScript-enabled Netscape Navigator 3.0.

Questions or comments should be addressed to the [ECCSite! Webmaster](#)

URL: http://www.epi.umn.edu/health_survey/

Last Update: May 6, 1997